



Alzheimer's
Research
UK

Young onset dementia



Contents

- 04 What is young onset dementia?
- 05 Young onset Alzheimer's disease
- 09 Posterior cortical atrophy
- 10 Vascular dementia
- 11 Frontotemporal dementia (FTD)
- 14 Dementia with Lewy bodies
- 15 Parkinson's disease
- 17 Diagnosing dementia
- 19 Treatments
- 21 Help and support
- 22 How to take part in research
- 23 Research



Introduction

This booklet provides an introduction to young onset dementia, where symptoms start before age 65.

It's for anyone who is worried about themselves or somebody else, or for people who want to know more about different types of young onset dementia and how they are diagnosed.

The information here does not replace advice that doctors, pharmacists, or nurses may give you. If you are worried about your health, including memory, thinking, behavioural and communication problems, speak with your doctor as soon as possible.

The booklet was updated in March 2022 and is due to be reviewed in March 2024. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers, and the Young Dementia Network. Please get in touch using the contact details below if you'd like a version with references or in a different format.

If you have questions about dementia or dementia research you can contact the **Dementia Research Infoline** call **0300 111 5111** email infoline@alzheimersresearchuk.org
Or write to us using the address on the back page.



What is young onset dementia?

The word dementia is used to describe a group of symptoms – often including, but not limited to, thinking problems, confusion or mood changes that are severe enough to affect day-to-day life.

Dementia is caused by underlying diseases that affect how our brain cells work. There are many causes of young onset dementia, with Alzheimer's disease the most common. Alzheimer's disease accounts for around one in three cases of young onset dementia. There are similarities between the diseases that cause young onset dementia and dementia that affects people in later life (late onset dementia), but some diseases such as frontotemporal dementia (FTD) are more common in younger people.

This information will cover different causes of dementia that start to affect people under 65.

Young onset Alzheimer's disease

Although often thought of as a disease of older people, around five in every 100 people with Alzheimer's disease are under 65.

This figure may be higher as it can be more difficult to get a diagnosis at a younger age. When symptoms begin before the age of 65, it is known as young onset or early onset Alzheimer's disease. It usually affects people in their 40s, 50s and early 60s.

If you are worried about yourself or someone else who may be showing symptoms, talk to your doctor. They will be able to rule out other health problems such as vitamin deficiencies that may cause similar symptoms in younger people. They may also refer you to a specialist for further tests if necessary.

Symptoms

While the symptoms of young onset Alzheimer's disease can be similar to those of late onset Alzheimer's, they can also affect younger people in more unusual ways. This can make it more difficult for people, families, and doctors to recognise and diagnose what is causing someone's symptoms.

Symptoms of young onset Alzheimer's disease can include:



Memory problems that interfere with everyday life. This may include forgetting a work meeting or recent events that would normally be remembered, or repeating questions.



Changes in personality and behaviour. These may be subtle at first. People may become low in mood, irritable, lose their confidence or show less interest in activities they used to enjoy.



People can have difficulty recognising objects and judging speed or distance. When visual problems are a leading symptom, the cause may be posterior cortical atrophy.



People may become confused in unfamiliar situations and lose a sense of place and time.



Difficulty finding the right words and communicating. This is called aphasia.



Daily tasks like paying bills, cooking and driving may be noticeably affected.

If you are concerned about your memory, thinking, or any of the above symptoms, speak to your doctor.

Causes

In the majority of cases, the cause of young onset Alzheimer's disease is a combination of our lifestyle, genetic and environmental factors. Research is ongoing to understand why some people are affected at a younger age than others.

Most cases of Alzheimer's are not directly inherited. However, cases below the age of 65 are slightly more likely to be inherited compared to late onset Alzheimer's.

Directly inherited Alzheimer's is where a parent with the disease passes a gene on to their children, who also then develop the disease. Around 11% of cases of young onset Alzheimer's may be directly inherited. This is sometimes referred to as familial Alzheimer's.

Three genes - APP, PSEN 1 and PSEN 2 - have been found to play a role in the development of familial Alzheimer's. Mistakes in these genes (called mutations) can cause the build-up of a toxic protein called amyloid in the brain, which is a key feature of the disease.

If someone has a strong family history of Alzheimer's starting at a young age, a doctor can refer them on for genetic counselling.

For more information, ask for our booklet '**Genes and dementia**'. Contact and order details can be found on the back of this booklet.



Will young onset Alzheimer's disease progress faster?

Diseases that cause dementia, like Alzheimer's, are progressive. This means that symptoms get worse over time and people require more support with their everyday lives. It is difficult to know whether young onset Alzheimer's progresses faster. There is some evidence that this is the case, but every person's experience of the disease, including how fast or slow it progresses, is different.

Difficulties with diagnosis in younger people may mean that they are diagnosed later, making their progression seem faster.

For more information, ask us for our booklet '**What is Alzheimer's disease?**' or talk to your doctor about the condition.

Posterior cortical atrophy

Posterior cortical atrophy (PCA) is a rare form of dementia usually affecting people between 50 and 65. It usually begins by affecting a person's vision.

PCA is caused by damage to brain cells at the back of the brain. This is the part of our brain that processes information from our eyes and allows us to make sense of what we are seeing and where things are.

Alzheimer's disease is the most common cause of brain cell damage in PCA, but it can also be caused by other types of dementia, such as dementia with Lewy bodies. People living with PCA have symptoms that vary from person to person and can change over time. Most people will have problems with their vision first, but some people may have problems with dressing, handwriting, coordination, numbers, and language too.

For more information on posterior cortical atrophy, please request our health information booklet '**What is posterior cortical atrophy?**' or speak to your doctor.

The **Rare Dementia Support PCA group** provides opportunities for people with PCA to meet each other and share their experiences. You can contact them by phone on **0203 325 0828** or email **contact@raredementiasupport.org**



Vascular dementia

Vascular dementia is the second most common cause of young onset dementia, accounting for around one in every five cases.

Vascular dementia occurs when blood vessels in the brain are damaged. This affects how our brain cells work and causes them to become damaged too. This can lead to symptoms like memory and thinking problems. There can also be more specific symptoms depending on the area of the brain affected. Vascular dementia can occur after a stroke, or due to small vessel disease (long-term damage of the smaller vessels in the brain) which can be caused by high blood pressure.

For more information on vascular dementia, please request our health information booklet **‘What is vascular dementia?’** or speak to your doctor.

Frontotemporal dementia (FTD)

Frontotemporal dementia, also known as FTD, often occurs in people under the age of 65. FTD accounts for around 12 in every 100 cases of young onset dementia. FTD often begins between the ages of 50-60.

In FTD there is damage to cells in areas of the brain called the frontal and temporal lobes. These areas of our brains control our personality, emotions and behaviour, as well as speech and understanding of words. There are several different types of FTD, and symptoms vary depending on which parts of the frontal and temporal lobes are affected.

For more information on the different types of FTD, please request our booklets **‘What is frontotemporal dementia?’** and **‘What is primary progressive aphasia?’** or talk to your doctor.



Symptoms can include:

- **Changes to behaviour:** being inappropriate, or a change in sense of humour.
- **Emotion:** a change in how people express their feelings, or understand other people's feelings.
- **Awareness:** people may not realise they are experiencing changes to their behaviour and emotions.
- **Words:** having trouble using the right word – often saying another word or using a vague term like 'thing' instead of a specific object.
- **Concepts:** for example not understanding that money is used for buying things, or that the remote controls the TV.
- **Communicating with others:** slurred or hesitant speech, which may be hard to understand.
- **Understanding:** finding it hard to understand long and complex sentences, this can affect reading and writing too.
- **Movement:** stiff or slowed bodily movement, weakness and twitches or cramps.



People with FTD can find it harder to swallow, eat, communicate, and may have difficulties with bladder or bowel control as symptoms become more severe. Some people may develop movement problems similar to those seen in motor neurone disease.

Frontotemporal dementia is a progressive disease, so over time symptoms get worse, and someone will require more support to look after themselves and with day-to-day activities. The speed of change in symptoms can vary widely from person to person.

Causes

In FTD, there is a build-up of proteins in the frontal and temporal lobes of the brain. Three proteins are involved in FTD, called tau, TDP-43 and FUS. These proteins clump together and damage the brain cells, eventually causing them to die. Several genes that are linked to a higher risk of developing the disease have been identified. Ongoing research is trying to understand more about how mistakes in these genes can lead to FTD.

In young onset FTD, about one in 10 cases are caused by a directly inherited gene. This is passed down from a parent who is affected to their child. The chances of passing the gene onto a child is 50/50 (one in two chance). This type of FTD is called familial FTD and there is a strong pattern of inheritance in every generation. If you're worried about this type of FTD, speak to your doctor who can refer you for specialist testing called genetic counselling.

To read more about this, please request our booklet '**Genes and dementia**'. In most cases, the cause of FTD is still unclear. It is likely to be a combination of our lifestyle, environment, and genetic factors.

Dementia with Lewy bodies

Around one in 10 cases of young onset dementia is caused by dementia with Lewy bodies.

Dementia with Lewy bodies is caused by small round clumps of protein called alpha-synuclein. The clumps it forms are called Lewy bodies. Lewy bodies damage the nerve cells, and this damage affects the way that our brain cells communicate.

Dementia with Lewy bodies can cause common dementia symptoms like memory loss and confusion, as well as other symptoms, like changes to alertness and hallucinations (or seeing things that are not there). Everyone's experience of dementia symptoms can be different, but most people have changes to their thinking, memory and behaviour that get worse over time.

Dementia with Lewy bodies is closely related to Parkinson's disease. The build-up of Lewy bodies is also found in Parkinson's, and leads to symptoms like movement problems and tremors. These symptoms can also occur in dementia with Lewy bodies.

For more information on dementia with Lewy bodies, please ask for our booklet **'What is dementia with Lewy bodies?'** or talk to your doctor.



Parkinson's disease

Parkinson's disease is most commonly diagnosed around 60 years old. Over half of people with Parkinson's go on to develop dementia, usually about 10 years after their diagnosis.

Parkinson's disease affects brain cells that produce a chemical called dopamine. The brain uses dopamine to send messages which control the body's movement. When the brain cannot produce enough dopamine to control movement properly, symptoms of Parkinson's begin to appear. As more brain cells are affected, problems with movement will get worse.

Symptoms

The three main symptoms of Parkinson's disease are:

- **Tremors**, causing arms or legs to shake.
- **Slow movement**, which can lead to slow, shuffling walking.
- **Muscle stiffness**, which can result in painful cramps.

Talk to your doctor if you are concerned about any of these symptoms.

Causes

Cases of people passing Parkinson's disease onto their children are very rare. However, some genes have been identified in a small number of people that increase their risk of developing the disease. People who receive a diagnosis of Parkinson's disease earlier in life are more likely to have a genetic link. In the vast majority of cases, the cause is still unclear. It is likely to be a combination of our lifestyle and genetic factors.

For more information and support for Parkinson's disease, please contact **Parkinson's UK** at **0808 800 0303** or email **hello@parkinsonsuk.org**



Diagnosing dementia

Diagnosing dementia early is important. You will be able to get the right help, treatments and support and plan for the future. You may also be able to take part in research studies. You should speak to your doctor about your concerns as soon as possible.



The doctor will:

- Ask about your symptoms and medical history and may give you a physical check-up.
- Ask you to do some memory and thinking tests.
- Run other tests, like blood tests, which may help the doctor to rule out other common causes for your symptoms like thyroid disorders or vitamin deficiencies.
- If you are under the age of 65 and your doctor suspects dementia, they should refer you to a memory clinic or a specialist for further tests.



A memory clinic or specialist may do:

- A brain scan to look for changes in the structure of your brain or to rule out other causes of your symptoms.
- In-depth memory and thinking tests.
- A lumbar puncture which can help look for "markers" of the diseases that cause dementia in your spinal fluid.

People who experience dementia symptoms at a younger age can often struggle to get a diagnosis or referrals, and the process can take longer than it does for someone over the age of 65.

This is in part because young onset dementia is less common and more likely to present with unusual symptoms. So, some doctors may not recognise dementia symptoms in younger people or put it down to other common conditions like stress, depression or menopause.

If you are struggling to get a diagnosis you can ask for a second opinion from another doctor. Keep a diary of your symptoms and how they affect your everyday life, as this can be helpful to show doctors when you have appointments.

You can also contact **Dementia UK's Admiral Nurses**, who are dementia specialist nurses on **0800 888 6678** or **helpline@dementiauk.org** They can advise people who are struggling to get a diagnosis.

For more information on getting a diagnosis of dementia, please ask for our booklet '**Problems with your memory?**' or the '**Personal checklist**' produced by Young Dementia Network that can aid discussions with your doctor about symptoms.

Treatments

There are treatments available on prescription that can help relieve some symptoms of young onset Alzheimer's and dementia with Lewy bodies.

These include the following drugs, known as cholinesterase inhibitors:

- donepezil
- rivastigmine
- galantamine

These drugs are licensed and recommended for people with mild to moderate symptoms of **Alzheimer's disease** and **dementia with Lewy bodies**.

Another drug called memantine may be given to people with these conditions who have moderate to severe symptoms, and to those with moderate symptoms when cholinesterase inhibitors don't help or are not suitable.

Those with moderate or severe symptoms may also be offered combination therapy, where a cholinesterase inhibitor is given in addition to memantine.

These treatments don't slow down the underlying disease, but they can help with some of the symptoms.

Unfortunately, there are currently no medications available to treat **frontotemporal dementia**, so the focus is on helping people with the disease manage their symptoms in everyday life.



There are currently no specific treatments for **vascular dementia**. However, a doctor may prescribe or monitor medicines taken to treat the underlying conditions that can damage blood vessels and contribute to vascular dementia.

There are several types of cognitive therapy that may benefit people with young onset dementia. For example, cognitive stimulation activities are designed to encourage thinking skills and engage people who have dementia, with an emphasis on enjoyment and group activities. The benefits of cognitive stimulation for people with dementia can include improvement in mood, thinking skills and quality of life.

For more information about all the treatment options talk to your doctor or request our free booklet '**Treatments for dementia**'.

Help and support

The impact of young onset dementia can be significant – people are often working, have financial commitments like a mortgage, and may have children still living at home.

There are organisations that offer advice, information, care, and practical and emotional support.

Dementia UK's dementia specialist **Admiral Nurses** offer practical advice and support to people affected by dementia and their families. They can be contacted on **0800 888 6678** or **helpline@dementiauk.org** You can ask them about services available in your area too.

The **Young Dementia Network** is a free-to-join influencing community of people with young onset dementia, their families, and professionals from health and social care, and the voluntary sector. Members work to improve support through creating resources, sharing information, offering opportunities for involvement and collaboration, and promoting a better understanding of young onset dementia. Find out more at **www.youngdementianetwork.org**

If you have questions about young onset dementia, symptoms, diagnosis, treatment, or about taking part in research you can contact the **Dementia Research Infoline** on **0300 111 5111** or **infoline@alzheimersresearchuk.org**

How to take part in research

People with and without dementia, and dementia carers are needed for research studies.

If you're interested in taking part in research and would like to find out more, register to the **Join Dementia Research** service, which is run by the NHS. This will match you to research studies you are suitable for, so you can see what type of research you could take part in. You can find out more and register here www.joindementiaresearch.nihr.ac.uk. You can also register over the telephone on **0300 111 5111**.



Research

Alzheimer's Research UK has funded over **£160 million** of pioneering research into many different kinds of dementia, including young onset dementia.

Several studies are looking at the genetics of young onset dementia, and another is working with people with young onset dementia, including FTD and Alzheimer's, to follow their health over several years. Our studies are helping to increase understanding of the disease, improve diagnosis and develop potential new treatments.

Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We provide free dementia health information, like this booklet and others. If you would like to view, download or order any of our other booklets please details below.

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